

The Underserved and Health Information Technology- Issues and Opportunities

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Introduction and Objectives

NORC at the University of Chicago is pleased to present this white paper entitled “The Underserved and Health Information Technology: Issues and Opportunities” for the Assistant Secretary for Planning and Evaluation (ASPE) at the U.S. Department of Health and Human Services (HHS). Due to recent advances in technology and greater attention to problems associated with quality and efficiency of health care delivery, we see new opportunities to improve the health and health care for underserved Americans through the use of emerging information technologies.

President George W. Bush announced an Executive Order in 2004 prioritizing the adoption and use of health information technology (health IT) by patients and providers as well as the use of secure health information exchange (HIE) to improve the quality, safety, effectiveness and efficiency of health care delivery in the United States, and creating the Office of the National Coordinator for Health IT (ONC). Several agencies within HHS including the Health Resources and Services Administration (HRSA), the Indian Health Service (IHS), the Office of Minority Health (OMH), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Medicare and Medicaid Services (CMS), the Office of Disease Prevention and Health Promotion (ODPHP), ASPE and others had been working on programs and policies to assure that the nation’s most vulnerable Americans are not left behind as the health care sector moves to adopt a more automated information driven approach to promoting health and preventing and treating illness. More recently several States have joined in these activities by sponsoring their own programs to encourage health IT adoption.

This purpose of this paper is to summarize a selected set of programs, policies and research findings that demonstrate both the potential for health IT to improve health and health care to underserved Americans as well as the challenges and barriers facing effective use of these technologies. We will attempt to cover an array of technologies including electronic health records (EHRs), e-Prescribing (eRx), chronic disease registries and clinical decision support systems (CDS) by health care providers predominantly serving the underserved. Additionally, we will examine technologies such as personal health records (PHRs), messaging and reminder systems, patient kiosks and other technologies that are “patient facing” where the theory is that IT can empower patients to take more control over their own health information and health care.

Finally, we will provide summary conclusions regarding what is known and yet to be understood regarding use of health IT among the underserved and highlight areas where further programmatic, policy or research activities sponsored by the federal government or others may be important. We begin with a brief discussion on health and health care challenges facing underserved Americans.

Why Focus on the Underserved?

While there is no single, universally accepted definition of the underserved, for the purpose of this paper, we characterize this population simply as those living in the United States who do not have adequate access to health care services. They share one or more of these characteristics: they may be poor; uninsured; have limited English language proficiency and/or lack familiarity with the health care delivery system; or live in locations where providers are not readily available to meet their needs. Members of ethnic and racial minority groups are not by definition “underserved”, but are disproportionately found among their numbers. Disparities in health status and access to health care that leave these populations worse off relative to others have been well documented by HHS over the last fifteen years.

Of the diverse set of groups represented among the underserved, perhaps disparities in health and health care of racial and ethnic minorities have been most thoroughly documented. Recently the Commonwealth Fund released a chart book analyzing data on the status of racial and ethnic minorities in the United States (available at <http://www.commonwealthfund.org/publications>). This effort compliments the primary federal government publication on health disparities, the “National Healthcare Disparities Report”, released annually by AHRQ with the last release for 2007 occurring in February of this year (available at <http://www.ahrq.gov/qual/qrd07.htm>).¹ Findings from both publications demonstrate persistent disparities in health status, access to health insurance, access to critical health care services such as a primary care, home and specialty care, and in the quality of care received by disadvantaged groups.² The Commonwealth summary shows that as of 2006, data from surveys conducted by federal agencies including AHRQ, the National Center for Health Statistics (NCHS) of the Centers

for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) demonstrate higher rates of self-reported poor health status, chronic disease and disability, life expectancy at birth, obesity, cancer (especially breast and colorectal), heart disease, diabetes, HIV/AIDS and other chronic illnesses among blacks compared to non-Hispanic whites in the United States. The chartbook also demonstrates specific types of behavioral and health status disparities for other racial and ethnic groups such as higher smoking prevalence and mental distress among American Indian and Alaska Native populations, and higher incidence of some infection-related cancers among Hispanics.

In terms of access to health care, the Commonwealth chart book shows greater percentages of Hispanic adults and adults of other racial and ethnic minorities reporting they have no doctor compared to whites, with the Hispanic average for this question being 2.5 times that of whites. They also show that blacks and Hispanics are less likely to report private physicians as their usual source of care relative to whites and are more likely to report going to community health centers and emergency rooms as their usual source of care or having no usual source of care. Hispanics also are much more likely than whites to report being uninsured during a given year. Some of these disparities are heavily mediated by income and are reduced or eliminated by controlling for this characteristic, suggesting the importance of viewing the low income population broadly as part of the underserved. However, many of these disparities, particularly as they relate to health status among blacks and access and insurance disparities issues among Hispanics persist even after adjusting for income.

Finally, the data on racial and ethnic disparities also demonstrates important differences in the quality of care delivered to ethnic and racial minorities. Primary care physicians who treat predominantly black patients report being unable to provide high quality care to all of their patients at a higher rate than similar physicians who treat a predominantly white population. Hispanics and Asians, on average, report wait times longer than others to get a doctor's appointment. Hispanics also report being less likely to have received recommended screenings such as blood cholesterol and cancer screenings (colorectal and cervical) relative to others. Racial and ethnic minorities in general are less likely to have received a pneumococcal vaccination, a dental visit in the past year (for children), and first trimester prenatal care (women) than the equivalent non minority populations.³

Racial and ethnic minorities aside, evidence from research shows that low-income populations generally experience more disjointed care, being twice as likely to lack a regular source of care.⁴ Those with low socioeconomic status (SES) have limited access to quality health care as it relates to primary, specialty, dental and behavioral care relative to others.⁵ Additionally, lower SES patients experience lower rates of preventive care and chronic disease management.^{6 7} We found no definitive evidence that rural residents, as a group, experience lower quality care; however, low population density in rural areas makes care less convenient and more costly. Additionally, rural populations are more likely to be uninsured and of low income, making these areas more susceptible to the barriers faced by low-income populations.⁸

The AHRQ National Healthcare Disparities report cited above focuses heavily on disparities in measures that address quality of care. AHRQ and the Inter-Agency HHS work group that contributes to this report provide data on 211 measures including 41 core measures on quality and access. Comparisons are produced across various demographic groups including blacks compared to whites, Asians compared to whites, Hispanics compared to non-Hispanics, poor compared to high income and American Indian and Alaskan Native compared to whites. Findings from the latest version of this report for 2007 show some reduction in previously identified disparities facing segments of the underserved for measures such as adequacy of hemodialysis treatment and childhood vaccination rates for blacks versus whites. However, the findings also demonstrate the persistence of disparities and little or no improvement over time in the disparities associated with many measures since the start of this initiative.⁹

Given findings from the research and analysis presented above, as well as a wealth of additional evidence suggesting similar trends of poor health and access to quality health care among groups comprising the underserved, improving care to this group represents an important challenge for policy makers and program leaders in federal and State government. Some have speculated that increased automation in health care and use of advanced IT could exacerbate rather than address these disparities if a "digital divide" threatens to leave underserved populations behind, resulting in a situation where only those who have historically enjoyed steady health insurance and access to private medical providers would benefit from these advances. At the same time, many of the most promising potential improvements in care due to health IT adoption including clinical decision support to alert providers to the need for increasing use of screenings, preventive care, and behavioral counseling

and patient registries that facilitate active management of chronic illness, could be of disproportionate benefit to the underserved. Finally, as the use of technologies such as PHRs serve to empower patients to take a more active role in their health care and overall well-being, it is increasingly important to recognize and address barriers to making the benefits of these technologies readily available to underserved populations who stand to benefit the most.

What Role Can Health IT Play?

Researchers have struggled to definitively characterize all the factors associated with disparities in health and health care for the underserved and assign appropriate importance to each factor. There is, however, a consensus regarding the significance of these problems and a solid interest among program and policy leaders to understand the manner in which advances in public health, health care delivery and health care financing can work to address these disparities. While it is clear that these disparities are a result of a complex network of factors including personal, family, cultural, neighborhood and economic variables in addition to those associated with the direct provision of necessary health care services, many have identified health IT as a means to facilitate behavioral and organizational changes to improve the health and health care of the underserved.

For the purpose of this paper we define health IT as technology that enables patients and providers to support better health and health care by providing targeted information meant to inform, educate or generally allow for improved decision making. In some cases, the information provided by these technologies is traditionally accessed by other means such as paper patient charts, evaluations and clinical summaries transferred via fax or by hand between providers or even clinical flow sheets that outline appropriate care for specific clinical situations based on accepted clinical guidelines.

Exhibit 1: Health IT Applications ¹⁰

Product or Functionality	Description
Electronic Health Record (EHR)	An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization.
Electronic Medical Record (EMR)	An electronic record of health-related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization.
e-Prescribing (eRx)	Enables a physician to transmit a prescription electronically to the patient's choice of pharmacy. It also enables physicians and pharmacies to obtain information about the patient's eligibility and medication history from drug plans. Often comes with built in alerts for drug-drug, drug-allergy and drug-disease interactions.
Personal Health Records	An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.
Computerized Physician Order Entry (CPOE)	Refers to a computer-based system of ordering medications and often other tests. Physicians directly enter orders into a computer system that can have varying levels of sophistication. Basic CPOE ensures standardized, legible, complete orders, and thus primarily reduces errors due to poor handwriting and ambiguous abbreviations.
Clinical Decision Support (CDS)	Any system designed to improve clinical decision making related to diagnostic or therapeutic processes of care. CDS addresses activities ranging from the selection of drugs (e.g., the optimal antibiotic choice given specific microbiologic data) or diagnostic tests to detailed support for optimal drug dosing and support for resolving diagnostic dilemmas. Often incorporated as part of CPOE or EMR/EHR systems.
Disease Registries	A database feature that includes key clinical data on a subset of chronically ill patients for the purpose of tracking their condition and managing treatment.

In other cases, health IT enables providers and patients to access information that they otherwise would not be able to access. Exhibit 1 above outlines some basic definitions of health IT applications. Implemented properly, these technologies can create tremendous efficiencies and improvements in health and health care by providing “the right information to the right person at the right time”. This results in benefits such as greater adherence to evidenced based guidelines for screenings and vaccinations, better patient compliance with treatment instructions, reductions in medication errors and improved patient education.

As noted above, specific technologies that are most commonly referred to as health IT include electronic health records (EHRs) and personal health records (PHRs), the former being the systems used by providers to electronically record and maintain patient demographic information and information on activities, diagnoses and orders associated with a clinical episode, and the latter being an application for use by patients to access and update information related to their own health and health care or that of a family member or loved one. One key distinction between EHRs and PHRs lies in defining the locus of usage and control. EHRs are controlled and used primarily by the provider whereas PHRs are used and controlled by patients and their surrogates.

Additional applications include functionalities that may be considered add-ons to these core concepts, including clinical decision support (CDS) which in the context of an EHR would provide patient specific information on an appropriate course of treatment based on clinical effectiveness research; issue alerts if an order entered by the clinician is counter-indicated based on the patient's profile; or provide reminders regarding the need to order specific interventions such as screenings, vaccinations, blood tests or foot exams.

In addition to PHRs, other health IT applications aimed at patients include health kiosks, where patients could obtain information on health conditions or access to information on their own health and health care using publicly available computer terminals set up within the community. These may also include messaging systems that allow transmission of reminders, information to guide healthful behavior, or even direct communication with providers through email or short message service (SMS) messaging accessed via cell phones or personal digital assistants (PDAs). In a 2006 report entitled, "Expanding the Reach and Impact of Consumer e-Health Tools", the Office of Disease Prevention and Health Promotion at HHS identified a series of functions that might be considered some of the key potential benefits to patients using health IT. These functions included provision of health information to patients in a searchable format to help with researching treatment options; support for behavior modification and self management of a healthy lifestyle; access to online communities for interacting with others on health issues; and functions that allow joint management and tracking of treatment involving online collaboration between patients and clinicians.¹¹

Another use of health IT involves health information exchange (HIE) which refers to the electronic exchange of data on a particular patient in a secure format between relevant administrative and clinical stakeholders such as other clinicians, payers and patients themselves. HIE can enable more efficient exchange of data between different types of providers (e.g., ambulatory and acute care providers or between primary care and specialty care) or between providers and patients (EHRs to PHRs). Some HIE functionality can also be built into PHRs and EHRs to enable specific services such as electronic prescribing (eRx) and refilling of prescription medications, ordering tests, receiving results from clinical laboratories, and maintaining ready access to radiology reports and results from tests conducted in an inpatient environment.

A central premise of our paper is that health IT applications such as the ones described in Exhibit 1 represent potentially effective mechanisms for achieving basic goals associated with improving health, health care and access to care for the underserved. As has been often noted, there is no evidence to suggest that health IT adoption in and of itself will transform the health or health care of the underserved. However, if based in broader initiatives for increasing enrollment in public programs, improving quality of care, empowering patients through improved access to information and streamlining and simplifying health care delivery, health IT may be a critical ingredient to achieving important changes.

In particular, because all IT and systems initiatives are designed around managing information in a standardized and efficient manner, these technologies can play an important role in assuring that the right information, in the right format is available to the right person and the right time to improve family and provider decision making, improve access to care and better target resources. Over time, health IT applications may lead to a richer set of data from which population health care trends can be assessed, thereby contributing to the development of better knowledge on the causes of disparities affecting health and health care for the underserved, getting a better sense of the barriers to improving their status relative to those disparities and contributing to programmatic and policy initiatives informed by a richer set of data than are currently available.

In the remainder of this paper we describe in greater detail opportunities and challenges associated with the use of health IT to improve health and health care of the underserved. For the sake of simplicity, in some places we organize this discussion between those technologies that can be considered primarily provider facing, such as EHRs, and those technologies that are primarily patient facing, such as PHRs. We note however that this is a

somewhat artificial distinction as effective approaches to improving health may need to take advantage of technologies that enable direct electronic communication between providers and patients through direct messaging and are, in that sense, both provider and patient facing. We end the paper with summary conclusions for different health care sector stakeholders and address areas that merit further exploration through research and evaluation.

Current State of Health IT and the Underserved

Although there is little population-based research on the use of health IT by the underserved and those that treat them specifically, there is some evidence that the groups disproportionately represented among the underserved and those that treat them are currently less likely to use health IT compared to other groups. For example, in the paragraphs below we cite recent research that shows that lower income Americans, some ethnic and racial minorities as well as residents in rural areas are less likely to have broadband access and are less likely to use the Internet than others, that individuals who lack steady access to health care are less likely to go online to get health related information and that safety net health centers that disproportionately serve the poor and uninsured are less likely than other providers to use electronic health records.^{12 13 14 15}

On the other hand, other research suggests that the income and education related factors are not as important in predicting Internet use as it has been in the past and that among individuals who use the Internet regularly, there is no difference by income, age or gender in the propensity to go online for communicating with providers or seeking information on health and health care.¹⁶ There is also evidence that many safety net health care providers have adopted health IT through the support of federal grants and are leaders in ambulatory health IT use. It is important to note however that adoption and access to health IT does not automatically translate to improvements in quality of care or health status.

Most of the research conducted to date has been limited in scope, looking at the potential for specific health IT interventions to improve limited aspects of quality of care for minorities or other groups represented in the underserved populations. While there has been some survey work conducted examining the use of health IT among health care providers that treat the underserved, there is almost no information on the use of patient-facing health IT applications by underserved individuals and families in the United States. This is predominantly because the extent to which PHRs are used by any group within the United States is largely unknown but considered to be limited due to the novel nature of these technologies, lack of knowledge of them among the public, and limited availability of PHRs sponsored by traditional sources of health care information for patients: providers, payers and purchasers. There are currently efforts underway sponsored by AHRQ and others to elucidate these issues.¹⁷

Direct Use of Health IT by Underserved Populations

As noted above, there is no research that looks at underserved populations as a whole and assesses use of patient-facing health IT applications such as PHRs, health kiosks or SMS-based messaging to generate evidence on the prevalence of use or attitudes towards these technologies among underserved Americans. However, there are data that can be used as proxies to assess the extent to which these technologies are accessible to the underserved and the likelihood that they will be adopted in the near future. These proxies include evidence regarding access to and use of information technology and communications technologies by groups represented among the underserved generally and in the context of health in particular. We explore available evidence on these questions below.

Some differences persist between underserved populations and the broader population with regard to internet usage and online health information seeking behavior. While current estimates of Internet usage suggest that more than half of individuals in all income and racial and ethnic groups have access to the Internet and use it on a consistent basis, there is still evidence that some racial and ethnic minorities as well as lower income individuals use the Internet in lower proportions compared to the general population.¹⁸ Additionally, urban and suburban residents are more likely than rural residents to use the Internet regularly, with 77 percent of urban and suburban residents reporting usage compared with 64 percent of rural residents in 2006.¹⁹ Thus, it is reasonable to conclude that the underserved are less likely than others to have access to the Internet and, if they have access, use it on a less frequent basis than others.

There is also evidence that those with a longer history of Internet use and who visit the doctor regularly are more likely than others to go online to access information on health.²⁰ Again, this trend suggests that the underserved, may be less likely than others to use the Internet as a tool for improving their health or health care as they are

disproportionately “new” users of the Internet. However, it is important to note that recent research by both the Pew Internet and the American Life Project and the National Cancer Institutes National Health Information Trends Survey (HINTS) suggests that, among the group of individuals who are Internet users, income and education are not associated with use of the Internet for communicating with providers or seeking health related information.^{21 22}

Because the model for most patient-facing health IT applications involves use of the Internet as a major conduit for accessing, exchanging and maintaining information relevant to the health and health care of a an individual or family, many of these technologies may be less useful for underserved Americans compared to other groups.²³ While this may signal the importance of increasing general Internet access and usage among the underserved population, there is also evidence that Internet usage alone may not lead to adoption of patient-facing health IT applications among the underserved.²⁴ As such, developers of patient-facing health IT are increasingly looking to applications built on other platforms to meet the same objectives of giving patients access to the “right information at the right time” to make good decisions regarding their health. For example, there is increased attention to the potential of building health interventions around SMS or “text messages” via cell phones and PDAs. These interventions are meant to support maintenance of a healthy lifestyle by initiating reminders and alerts to patients or sharing test results and instructions with patients and there is some evidence, particularly from the developing world, that cell phones represent a cost effective medium for transferring critical health and health care messages to an underserved population.^{25 26}

Even though patient facing health IT applications are in early stages of adoption and usage, there are many targeted applications that have been developed, implemented and even evaluated on a small scale. In the ODPHP report referenced above, the authors identified and reviewed 40 separate “consumer e-Health tools” ranging from informational websites to PHRs with a vast array of functions. Selected examples of patient-facing health IT that are specifically targeted to underserved populations are reviewed below along with evidence regarding their success.

PHRs for migrant workers.²⁷ MiVIA, a PHR designed for migrant, Spanish-speaking populations in California, is web-based tool that allows for documentation of clinical visits, health conditions, allergies, medications and other information critical to maintaining continuity of care. Importantly, the tool also provides its target audience with other valuable services including a picture ID, a stable email address, access to Medline and provider websites and emergency ID information and is set up to allow access not only to the individual patient but also family and surrogates.

Finally, there is a provider view where clinicians are allowed to populate, view and update data on patients they are treating based on a specific episode of care. While we found no published independent evaluation of MiVIA, anecdotal information and internally conducted assessments suggest that a significant percentage of individuals signed up for and have accounts with MiVIA use it regularly. Additionally, clinicians report that use of MiVIA has dramatically improved their ability to provide effective health care to this highly mobile population.

Implementers of MiVIA note the importance of not simply making the tool available and publicizing it, but providing comprehensive education and support to assist individuals with every facet of using the application effectively. This included providing basic training on computer and Internet usage, providing information regarding locations where clients could access computers with Internet connections, as well as extensive repetitive training on the use of the application itself. Support and training are provided by “promoters de salud” or community health workers who are imbedded among the migrant workers and are able to conduct the training in a culturally appropriate manner using language that is familiar to clients. While MiVIA started as a local collaborative effort between labor and health care providers in Sonoma County California, it has expanded in recent years to other migrant farm communities on the West Coast and is being touted as a an optimal PHR solution for homeless individuals, children and others.

Online education and support systems for cancer patients.^{28 29} While MiVIA is an example of a relatively broad based PHR that is targeted to a specific demographic population regardless of their individual health status or needs, many patient facing health IT applications focus on providing targeted functionality to individuals who have similar health and health care characteristics. One such example is the Comprehensive Health Enhancement Support System (CHESS) developed by the University of Wisconsin and the Cancer Information Service (CIS) which is part of the National Institutes of Health’s (NIH), National Cancer Institute (NCI). CHESS is an online

system that provides users with 11 services designed to improve quality of life for women diagnosed with breast cancer.

These include what are referred to as “information services” such as a static “Q&A” section; a library of reference articles on breast cancer topics; and resource guides on topics such as selecting providers, resource directories and links to other useful sites. In addition, the system offers “support services” allowing users to ask direct questions to clinical experts and gain emotional support by viewing text and video accounts from other cancer patients discussing how they coped with the disease. And, finally, it provides “decision services” that allow users to take emotional status assessments and receive tailored advice on coping, and use online health charts to track their health status. These health charts also direct users to information on their own specific health concerns and decision aids that help identify options, assign values, and elucidate potential consequences associated with key treatment and lifestyle decisions.

Recently published literature on the system demonstrates that CHES is effective in improving social support, comfort with their doctors and the care they are receiving, information competence and quality of life among women with cancer. Research also suggests that CHES is particularly effective on these measures for women considered “disadvantaged” based on income and insurance status because these individuals are the ones that are most likely to lack any resources in the absence of having access to a system such as CHES.

In a subsequent study, researchers assessed the relative effectiveness of different approaches to disseminating and encouraging take up of CHES among underserved women and found that while referrals from hospitals and doctors were effective in encouraging underserved women to make use of CHES, different approaches were important for different communities. For example, they found that publicizing CHES through radio advertisements was more effective among black women compared to others. They also demonstrated the benefits of extensive in person training for underserved women, not only on navigating and using CHES, but more basic skills around use of computers and the Internet.

Using health kiosks.^{30 31} Standalone health kiosks offer some of the same functionality of PHRs and online support systems, but combine computer hardware and software in a single unit. This combination helps to address issues surrounding computer and internet access among some underserved groups. Additionally, physically placing kiosks in targeted locations (such as physician offices or health centers) could allow trained health assistants to assist users when needed. Hardware and software specifications also allow kiosk designers to limit internet and data access to a greater degree than would be possible in a home web-based system. In one pilot implementation among Australian aboriginals, health kiosks served as a first step toward greater health IT familiarity. The kiosks helped to address the connectivity and hardware issues facing those with the most limited experience with and access to new technologies.

Closer to home, a project initiated by the Duke University Medical Center tested the potential impact of kiosks to address the needs for underserved residents in North Carolina³². Duke created a cluster of nine health kiosks in three counties in the state. DERICKs (Durham e-Health Resource Information Center Kiosks) are located in community health centers, medical centers, local departments of social service and emergency departments. The kiosks are used to help patients identify and overcome personal barriers to accessing care (e.g. transportation issues may lead the kiosk to recommend contacting a local transportation agency). To that end, the kiosk asks a series of preliminary questions to gauge users’ language preferences, education and literacy levels and levels of computer literacy. The responses to these questions help to tailor the questions related to access later in the kiosk application. All kiosk text is available in both English and Spanish and videos are available to walk users through all steps in the process. Users are also able to print out pamphlets via a built-in printer. These pamphlets document specific resources and provide customized guidance to help overcome barriers to better health. To date, the average DERICK user prints out three pamphlets.

While anyone can use DERICKs, they offer additional functionality for Medicaid beneficiaries. DERICK allows users to enter their Medicaid ID numbers. DERICK documents beneficiaries’ barriers and transmits them electronically to their assigned case managers. This provides another point of access to the social service safety net for beneficiaries who may not have time to update their case managers after every ED or primary care visit. Data gathered through kiosks are transmitted through a local HIE, COACH (Community-Oriented Approach to Coordinated Healthcare). This connectivity allows other local providers to access information gathered via

DERICK. While specific details remain unclear, Medicaid beneficiaries may be able to access medical records using kiosks in the future.

Others in the field have expressed greater skepticism toward the use of health kiosks. While customization for targeted populations is a clear benefit for underserved groups, little has been done to clarify what such changes would look like. Additionally, some research indicates that any benefit to the low running costs of health kiosks would be negated as health kiosk user satisfaction generally wanes over time. High initial costs suggest that health kiosks could amount to an expensive novelty for underserved communities.

Use of text messaging system. One emerging set of interventions aimed at improving the health of the underserved through use of health IT takes advantage of wide adoption of cell phones that use SMS technologies to enable text messaging of health content directly to specific targeted populations. One of the several innovative projects initiated by the Robert Wood Johnson Foundation (RWJF) as part of their Project Health Design PHR initiative takes advantage of the fact that some populations making up the underserved are more likely to have cell phones than regular access to personal computers or laptops. For this initiative, RWJF developed the prototype for a system that would allow patients with heart disease to report on their status on a daily basis and then receive tailored information regarding recommended therapies and behaviors for that day.³³

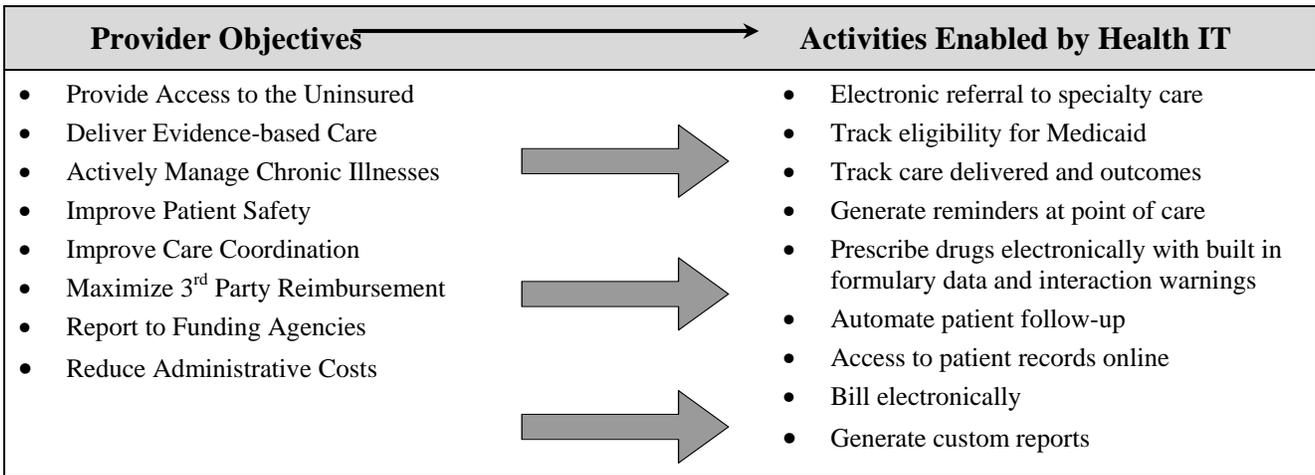
This project based at the University of Rochester aims at developing a prototype portable digital assistant with more functionality than the vast majority of cell phones (e.g., sophisticated speech recognition). It does, however, reflect an important opportunity for use of cell phone based text messaging to allow for bi-directional communication. A similar Project Health Design project looks specifically at design issues for interventions that seek to help teens with chronic illness transition from pediatric and adolescent care to adult health care. This project focuses heavily on leveraging existing behaviors among teens, for example text messaging, to facilitate the exchange of information on chronic illnesses.³⁴

Finally, though there are some differences in priorities and needs, health improvement projects from the developing world do offer some evidence of “proof in concept” for text messaging based interventions to improve health. A project sponsored by “Compliance Service” a private company in Cape Town, South Africa, has demonstrated, by their own assessment, an effective method to encourage compliance with medication therapy for patients with tuberculosis using targeted SMS-based reminders. This project makes extensive use of open-source software applications and low cost messaging services to address one of sub-Saharan Africa’s most important public health concerns.³⁵

Health IT Use Among Providers Treating the Underserved

There are numerous models by which use of health IT by health care providers either on a community or institutional level can facilitate more effective and efficient delivery of care. Exhibit 2 below outlines some basic objectives of health care providers and demonstrates how health IT functionality can assist in meeting those goals.

Exhibit 2: Health IT Functionality and Health Center Mission



It should be noted that existing research on EHR adoption nationally shows relatively low rates of adoption, with estimates ranging from 4 percent for adoption of a fully functional EHR to 17 percent for any form of EHR using consensus based definitions.³⁶ A survey of EHR adoption among federally funded community health centers that treat predominantly low income individuals demonstrates that these providers are less likely than private physicians to have adopted EHRs.³⁷ The study did show, however, that a majority of federally qualified health centers planned on implementing EHRs in the near future.

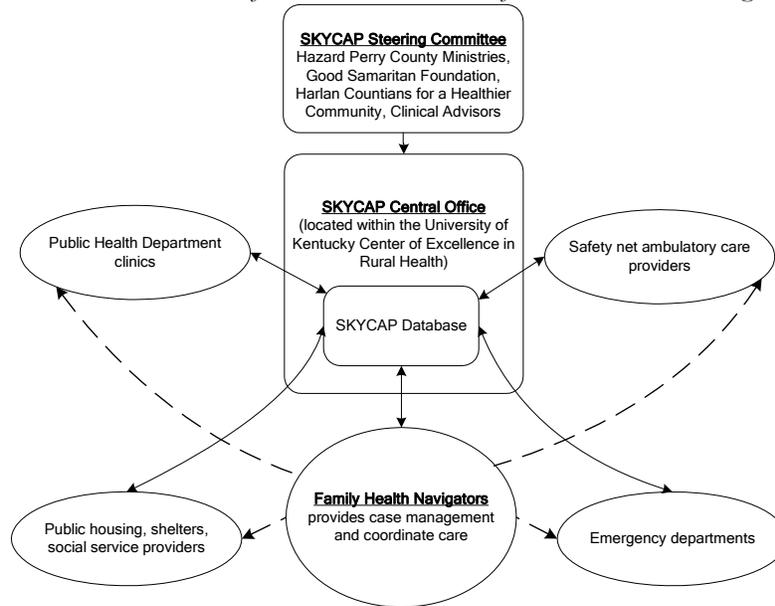
There are numerous examples of the adoption of health IT among health centers and health center networks and that these providers are committed to using patient registries to support quality improvement programs that are proven to improve processes and outcomes of care for patients with chronic illnesses such as diabetes³⁸. While still in their early stages, health center networks funded under a series of grant programs sponsored by the Health Resources and Services Administration (HRSA) have demonstrated that collaboration and pooling of resources and expertise can lead to broader scale adoption of EHRs among safety net providers and, with it, the potential to improve the quality of care delivered to the underserved³⁹.

Another example of effective use of health IT among providers of the underserved is the Indian Health Services (IHS) which has led the way in addressing the needs of a very complex and underserved population. Because they are mandated by Congress to serve a very specific population with a set of special health risks and needs, for decades the IHS has long used a population health approach to monitor and track the health and health care of their patients through a Resource and Patient Management System (RPMS). In 2007, IHS released a graphical interface designed to work with the RPMS as well as an application called iCare that allows for automated review and tagging of patient level information from RPMS to facilitate timely detection of risk factors and diagnosis of illnesses.⁴⁰ The interface along with RPMS and iCare represents a robust EHR with clinical decision support. IHS providers note that systems such as iCare that produce automatic alerts and suggest the likelihood that specific diagnoses and treatment approaches may be appropriate based on systematic, automated review of patient data can help maintain a high level of vigilance for opportunities to detect and prevent disease that disproportionately impact American Indian communities such as diabetes, childhood obesity and depression.

Finally, there are examples of community-based implementation of data warehouses and community tracking systems that seek to integrate patient-level data from providers caring for the underserved including information on demographics, clinical experience, health status and eligibility for public insurance programs in a system that is accessible to health care providers, case workers and other social service providers. These systems attempt to facilitate access to a range of social services. Several examples of these systems were initiated under the Healthy Communities Action Program (HCAP) and, while demonstrating some great potential, have proven difficult to sustain over time. Exhibit 3 below illustrates the model for one such program initiated in the state of Kentucky. The original program, known as SKYCAP originally, has subsequently changed its name to the “Kentucky Homeplace Program” after HCAP funding period ended. Kentucky Homeplace is currently funded by the Kentucky Department of Public Health and operates in Western, South Central, Southern, Southeast and Northeast Kentucky.

Exhibit 3: Overview of Kentucky Community Tracking database

Note: solid lines indicate data transfer; dotted lines indicate referral or other case management contact.



Issues Facing Use of Health IT in the Underserved

The preceding discussion demonstrates that while the underserved and their providers are in very early stages of making use of health IT, there are a wide range of attractive opportunities and at least several good examples of effective use of health IT to improve the health and health care of the underserved. The discussion of specific examples also illustrates some of the challenges inherent in making the benefits of health IT available for the underserved. While stakeholders responsible for using health IT to improve care to the underserved must also contend with significant challenges associated with the design, adoption, implementation and use of health IT generally, we focus for the following pages on those issues and challenges which are specific to the context of addressing the needs of the underserved.

Issues for Provider Facing Health IT

Providers who disproportionately care for the underserved often face different circumstances and barriers in effectively providing care. Some of these challenges reappear in implementing health IT among providers working with the underserved. For example, community health centers often work with patients who have complex mental and physical health needs.⁴¹ The complexity of these needs results in a an integrated services approach to care where medical care, mental health care, dental care and case management may be provided by the same institution. While these providers can help to fully address the needs of the most underserved individuals, the provision of a more holistic set of services can make health IT implementations more difficult. Robert Miller and Christopher West explain: “This complexity increases EHR-related costs for CHCs, because it increases the complexity of CIS changes, staff training, and complementary process changes.” Additionally, chronic resource constraints make the capital investments necessary for health IT a near impossibility.⁴²

While many of the concerns listed above are specific to community health centers and others that disproportionately care for the underserved, many of the barriers to health IT adoption in these settings resemble those faced by providers generally. Issues of workflow redesign, change management and health information exchange appear similarly difficult among those who care for the underserved and other providers. This similarity suggests that wider efforts to address some of the difficulties in health IT adoption may prove effective in underserved environments.

Despite the similarity in barriers, many point to differences in provider adoption rates as a clear sign that progress needs to be made in underserved environments. Some of the key issues and challenges facing safety net providers seeking to implement health IT are elaborated below.

Financing health IT. As might be expected, the most common issue or challenge associated with health IT adoption for providers caring for the underserved is the lack of access to capital to make necessary investments in the start-up and maintenance costs associated with health IT adoption. Because many of these providers are publicly funded, non-profit institutions such as federally qualified health centers or publicly funded hospitals operating on a low or no profit basis, they are not in a position to make significant capital investments that will not result directly in increased revenue through expansion of their patient base or scope of services. Federally qualified health centers also report feeling financially constrained due to limits on their ability to use grant funds meant predominantly to fund direct services to patients to finance health IT adoption that will enhance the overall quality and efficiency of the services they provide.

Vendor selection and customization. Given the diversity among individuals that could be considered among the underserved at any given time, providers seeking adoption of health IT for quality improvement must pay particular attention to the relationship between the health and cultural characteristics of their target populations and the features, functionalities and customization they will require from their health IT applications. For example, providers who treat a predominantly middle age to elderly African American population may want to assure that their EHR system supports diabetes registries and can transfer any registry data from legacy systems into the new application. In addition, providers treating the underserved often are funded from a variety of sources and are required to generate a variety of specified reports to those funders on a regular basis. Many EHRs have rudimentary applications for running custom reports, so it often takes additional resources and attention to assure that appropriate reports can be produced accurately and efficiently.

Finding the right strategy to empower patients. Given the importance of focusing on health IT as a means to the end of improving health and health care for underserved individuals, providers work to set up systems to best support a clinical workflow that provides the greatest opportunity of empowering patients to take an active role in the management of their own care. In the case of some underserved populations, this would require systems to prompt staff to conduct frequent reminders for patients who are due for specific clinical exams, vaccinations or diagnostic tests. How and when this prompting occurs (i.e., by phone, text message or email in the morning or the evening) may depend on circumstances (e.g., work hours, access to computers) of the individual patients as well as the hours of operation of the health center. Health centers that treat specific populations, e.g., homeless persons, day laborers, farm workers or low skilled or low waged employees may need to institute specific prompting strategies that reflect predominant characteristics among their patients. In addition, among some populations it is important that such prompts be directed to family members or surrogates in addition to the patients themselves.

Maintaining cultural competence and trust in a computerized environment. While there is limited information regarding the attitudes of patients generally with respect to health IT use among providers, some anticipate that patients will have concerns both related to the security and privacy of their health information if it is maintained and used in electronic form and in the potential erosion of some aspects of the doctor patient relationship if there is a computer mediating their interactions in the exam room⁴³. There is also some evidence that racial and ethnic minorities, new immigrants and other groups that are disproportionately among the underserved have less trust in the health care system than the general population⁴⁴. As such, it will be important for community leaders and public health officials to reach out to members of their patient community prior to health IT adoption to explain the benefits of health IT adoption and describe exactly how the care they receive and manner in which their health information is handled will or will not change. Furthermore, the extent to which providers refer to the computer during a clinical exam may be different for populations with limited English proficiency who may require more focused communication with the clinician to exchange critical information.

Issues for Patient Facing Health IT

While there are some significant issues specific to provider adoption health IT to address the needs of the underserved, the issues for patient facing health IT applications are more complex. In part this is due to the fact that highly functional patient facing health IT applications such as PHRs and clinical messaging systems are so new and there are still many challenges associated with their adoption by the general population. It is also due to the vast diversity of personal and community characteristics included among the underserved and the difficulty of any one application to perfectly meet all of their needs. Finally, there are likely some hard limits to what patient facing health IT can accomplish in the face of structural barriers to improved health and health care for some segments of the underserved. These topics and others are elaborated below.

Language and health literacy. Several researchers and authors have noted the significant challenges associated with developing consumer-targeted materials on health and health care issues⁴⁵. It is critical that these materials be comprehensive and accurate, while describing key concepts in terms that are digestible and well understood on the part of the intended audience. In some ways this information needs to be better understood than other materials that individuals may read, because they must understand the information well enough to feel comfortable taking direct action on the conclusions they draw. A Patient's health or quality of life may be directly affected by their ability to take the right action at the right time. Developing audience-appropriate guidance on health care is difficult and costs are compounded when one considers the need to develop materials in a series of different languages or when targeting populations with low reading proficiency in any language.

Technology literacy. As noted earlier in this paper, there is some evidence to suggest that some groups within the underserved population have limited access to computers and the Internet. Even as access to these technologies expands as it has dramatically in recent years, proficiency with use of these applications is highly variable in several key populations. For example, even individuals who are comfortable using the Internet to browse specific sites to obtain information may not feel comfortable enough to interact with others online or conduct financial transactions online. While training is an important component of rolling out any new application, in the case of patient facing health IT, training often need to comprehensively cover all aspects of successful use of the application, from the question of where and how one can access a computer with Internet access, to the basics of using a computer and Internet browser to view and submit information to more detailed training on the specific components and features of the application.

Fear and stigma attached to health problems. One potential barrier to adoption of patient-facing health IT applications and use of the health care system in general may be the fear of learning about and acknowledging health problems, and relatedly, the stigma associated with having particular health conditions in some communities⁴⁶. In these communities motivation for adoption of health IT and the very act of learning about health status and risk factors may be limited.

Structural issues barriers. While patient facing health IT applications can help empower patients by arming them with information relevant to the appropriate care and treatment, this information could be of limited usefulness if structural barriers prevent them from acting effectively in a manner consistent with the information they receive. Structural barriers that can prevent the benefits of having good information at the right time would include a dearth of health care providers for an uninsured or publicly insured individual, as well as the lack of public parks, bike paths and grocery stores in some communities to facilitate healthful living. While being armed with appropriate information from health IT can be tremendously useful to the underserved, its usefulness may be severely limited if structural barriers to health and health care prevent appropriate action.

Effective strategies for adoption. Finally, given individuals' busy lives and the potential that health and health care issues may not be the most important priority for some underserved families who are struggling for economic survival, it is clear that if patient facing health IT applications are to bring significant benefits to underserved populations, concerted effort must be put into place to make these tools widely and freely available, to educate underserved populations regarding the benefits of taking advantage of these tools, and to offer providers incentives to cooperate the establishment of integrated applications that allow patient and provider coordination on health and health care issues.

Our examples also demonstrate the desirability of coupling patient facing health IT applications with other services that are of immediate day to day use to underserved individuals. For example, one of the rationales behind adding the feature of maintaining a picture ID as part of MiVIA was to motivate individuals who may not otherwise be interested in signing up for a personal health care application to learn about and eventually begin using MiVIA.

Conclusions

While there is more work to be done, there are several experiences and examples to date that suggest that health IT may be an integral part of broader solutions to address disparities in the health and well being of underserved Americans. There is broad acknowledgement among key stakeholders that moving towards a more digital environment where health data, information and knowledge is generated, captured and shared securely, efficiently and in a targeted manner (right information to the right person at the right time) is an important structural step in improving the nations health care delivery system and public health system. It is important however, as these efforts

get underway, that appropriate attention is given to the particular needs of the most vulnerable Americans and the institutions that serve their needs to ensure that they are not left behind. We end with a set of conclusions for consideration by policy makers, payers and purchasers, providers and other health care stakeholders as the nation grapples with new approaches to address the health and health care needs of underserved Americans.

Health IT is a means to an end, not a magic bullet. It is important to recognize that health IT does not represent a magic bullet for improving health and health care to the underserved. As with use of health IT to improve quality of care in general, it is just an important component for facilitating these improvements and must be integrated into broader initiatives that focus on understanding and addressing root causes of these disparities, including structural barriers.

The promise is there, but structural and financial challenges persist. Work to date shows that attention to health IT use as it relates to improving health care and the health of the underserved can reap important rewards, in terms of access to care, quality and the patient-centeredness of health care. Federal, state and community based efforts have begun to show anecdotal evidence of improvement.

However, health IT generally, and patient facing health IT in particular, is still in the early stages of use among the underserved and the institutions serving them, and there has been limited formal study of its use and impact among underserved populations. One reason for the relative slowness of adoption relate to structural and financial challenges faced by this population and providers that serve them.

For example, most federally funded health centers and other safety net health care providers have limited financial margins with which to pursue solutions based in health IT adoption and lack the time and staff necessary to pursue federal grants to initiate this work either individually or as part of a consortium. Similarly, many underserved families are faced with a myriad of daily challenges to assure their own immediate safety and financial health and are less likely to have time to access to online tools to help manage their health and health care and may be less able to use these tools effectively.

Evidence of a digital divide diminishing but still may be a factor. There is still a clear relationship between income and access to the Internet.⁴⁷ However, there is increasing evidence that the digital divide, especially as it relates to age, income and education is diminishing.⁴⁸ There is also evidence, that among, individuals who regularly use the use Internet, there is no correlation between key income or education and one's likelihood to communicate electronically with providers.⁴⁹ However, other studies do suggest that individuals who have less access to traditional health care are also less likely to use online tools to get or exchange information about their health. What is clear, is that even at the lowest income levels the majority of adults in the United States now have access to and use the Internet and that this represents an important opportunity for patient facing health IT.

Training and education are essential to achieve potential benefits. As the underserved as a whole begins to get better access to IT and online tools, the question will become how to translate better access to these resources to improvements in health and health care. Pairing technology initiatives with human support and training appears to be the most significant way to increase adoption and promote effective use over time. In many pilot programs, in-person assistance helped to address unexpected barriers and population-specific challenges. It appears that few if any have been able to develop purely automated approaches to culturally appropriate training and support, although some have tried to make educational resources more culturally relevant. In some cases, in-person training and assistance also appears to overcome the negative effects of lower computer ownership and internet usage rates. It remains to be seen whether similar results can be duplicated by building training and support into the technology itself.⁵⁰

Personal computers are not the only mechanism for reaching the underserved. Lack of computer literacy may not be as large a problem as anticipated because of increased access to computers and the Internet among all families in the United States.⁵¹ Still, stakeholders should take lessons learned from other parts of the world where SMS, text messaging, and use of cell phones have been employed to facilitate improvements in population health.⁵²

Greater engagement between the community of providers, case workers and social workers serving the underserved and the health IT industry is needed. Community-based systems that facilitate sharing of individual level information across health care and social service providers offer the most promise for being able to address structural and multi-factorial barriers to health and health care improvement. However, these are difficult to sustain

because of the need for centralized coordination among distinct entities with limited financial incentive to coordinate and integrate.

Underserved communities are different from other communities and from each other. Evolving EHR and PHR certification efforts may be able to help address potential disconnects between the design of health IT applications and the needs of communities, safety net providers and the underserved themselves by offering special certificates to applications that meet requirements around treating patients with limited English proficiency or who may have special needs with respect to culturally competent care. However, it is also important to note that the underserved represent an array of different segments of our population and that health IT based interventions or approaches that work among one segment of the underserved will not work for all other segments. Understanding differences across segments of the underserved is particularly important for designing patient facing technologies that can be effectively used by a particular community for improving behaviors associated with better health.

Additional research is needed. Existing evaluation data focus on specific interventions and their impact on specific populations. More evaluation is needed on this level. In addition, more research is needed to systematically review and synthesize these studies and to draw broader conclusions regarding the potential impact of health IT on the underserved. Finally, it may be advisable for funders to work closely with researchers to identify consistent domains and measures for evaluation of the impact of health IT on the underserved to allow for meta-analyses or more robust syntheses across distinct evaluation efforts over time.

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